



# Sustaining community groups and activities for people affected by dementia

Recommendations from the **SCI-Dem Project** for  
**Commissioners and Policy-Makers**



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# Introduction

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Supporting people with dementia and their carers to live as well as possible in their own homes is a public health goal internationally, but also one of the greatest healthcare challenges we face. More than 850,000 people in the UK currently live with the condition, a number forecast to double to by 2040. There are currently significant gaps and inconsistencies in the support on offer to help people adjust, connect with others, access services and continue to live well, following diagnosis.

Community-based groups or activities for people affected by dementia can be a key form of support. However, these often struggle to keep going long-term once they have started. Policy and commissioning can play a significant role in creating a more favourable climate in which such groups and activities can sustain and flourish (and in turn, of course, groups can play role in patient and public involvement in planning and commissioning).

The SCI-Dem (Sustainable Community Interventions for people affected by Dementia) review has gathered together information about the common problems that face regularly-meeting groups in keeping going. This review primarily aims to share strategies and good practices for those running a community group or activity, but our data has also revealed information that might be useful and informative to those commissioning services or shaping policy.

This booklet outlines a summary of this information in the form of recommendations for commissioners, funders and policy-makers. A more in-depth report on the SCI-Dem review as a whole will be available (please contact us for more info). The data these recommendations are based upon was gathered and put together from dozens of varied sources: research studies, evaluation reports, magazine articles, info guides and how-to booklets, conference talks, even videos and artistic output from some groups.

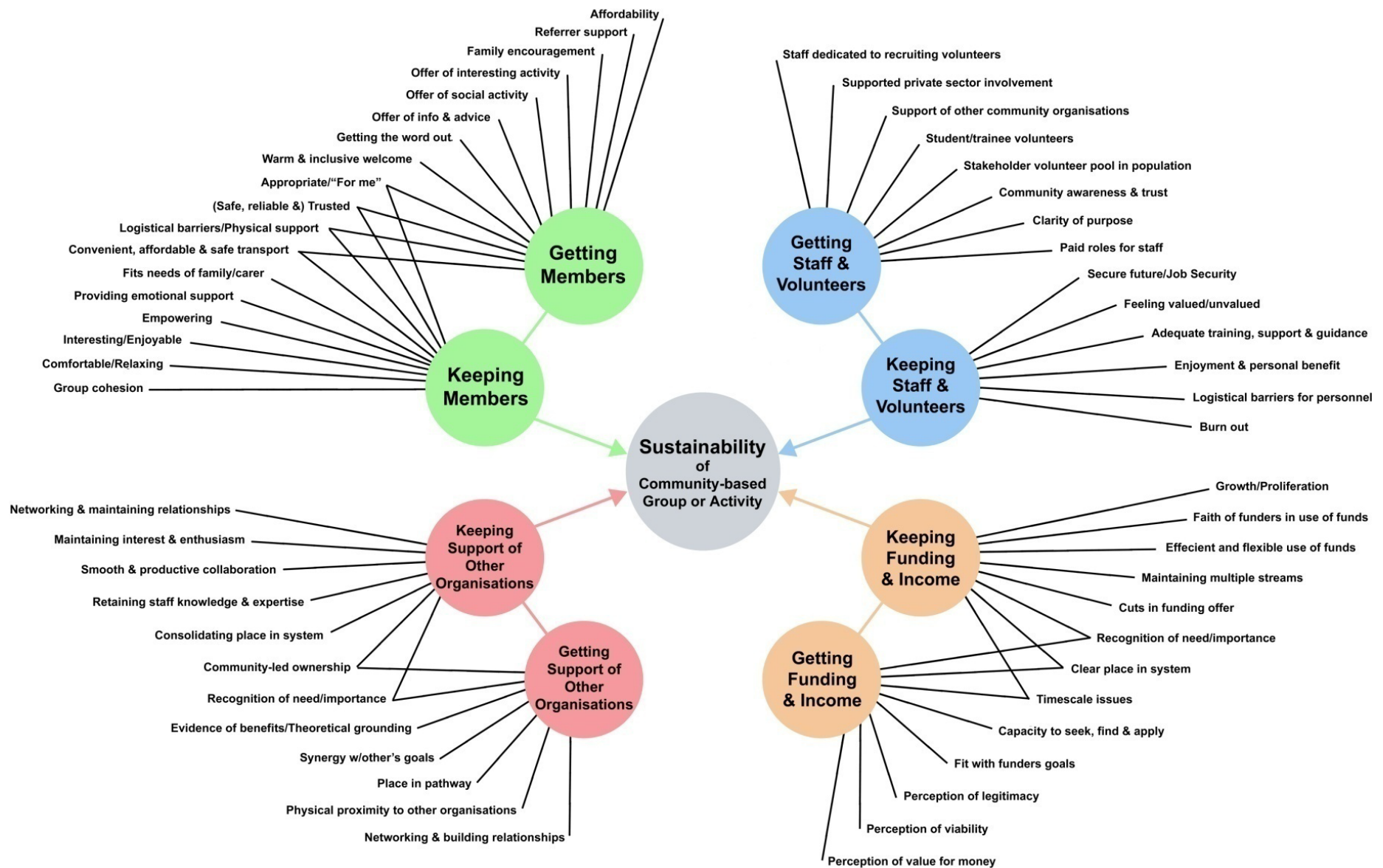
We hope that what we have found is of interest and provides something useful and informative when considering decisions on how to encourage community-based groups and activities that support people affected by dementia - and help them to keep going long-term.

## **FOR MORE INFORMATION ON SCI-DEM:**

SCI-Dem Project online blog: [scidemreview.wordpress.com](http://scidemreview.wordpress.com)

Email: [t.morton@worc.ac.uk](mailto:t.morton@worc.ac.uk) Twitter: [@ThomasMortonADS](https://twitter.com/ThomasMortonADS)

## Overview of factors contributing to sustainability (As found by the SCI-Dem realist review)



# Recommendations to commissioners and policy-makers

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## **1. Service users value the social side of an intervention highly, often more than the intervention or activity itself**

It is the social aspects of an intervention that tend to hold the widest appeal and keep people coming back. A relaxed social feel can also make coming along less intimidating and being connected socially is positive for both mental and physical health. This should be considered when commissioning, to ensure supported interventions are ones that people will want to go along to.

## **2. Service users need to feel an intervention is "for them" to want to attend and keep attending**

Meaningful activities that allow people to continue engaging with their interests will motivate people to come along. Groups that make an effort to recognise and respect people's history and culture are also more likely to attract and retain people. On the other hand, if those of different ages, needs and abilities feel "lumped in together" this can put people off as they may feel their particular needs are not understood or catered for. Again this should be considered to ensure supported interventions are ones that people will want to go to, and that meet their needs.

## **3. Lack of appropriate transport can be a major barrier to an intervention getting and keeping attendees**

If there is no affordable transport, or a venue is too far away, people will not go to attend an intervention even if they would like to. Equally, if transport isn't appropriate, reliable and respectful of people with dementia, they will not want to use it. Commissioners and policy-makers can help by focussing on improvements to community transport, especially in rural areas where this is a particular challenge.

## **4. Health and social care services that may refer to an intervention need incentive and guidance to do so**

Community interventions may be poorly understood by GPs and other health professionals, with criteria for referring unclear. If there are known bureaucratic problems such as waiting lists, a complex sign-up process or cross-border issues, this can also discourage referrals. If diagnosis is only made at later stages, then community interventions for people living at home may not be appropriate for those diagnosed. Extra incentive and guidance may be needed to help and encourage potential referrers to tackle such barriers.

**5. To retain staff and volunteers there needs to be adequate financial support in place for roles and activities**

When funding is limited and inconsistent, paid staff may be difficult to recruit and retain as they will not have job security. If unpaid volunteers are treated as a replacement, remaining staff may feel their roles are undermined and un-valued. Likewise if volunteers are treated as “coming for free”, they may feel their time and expertise is taken for granted, and may be very limited in terms of how much they can do. Some form of financial support is necessary for both in the long term.

**6. Established community organisations, including local authorities, can offer help in a number of ways to enable small-scale interventions to flourish**

Having help with a venue, resources, training, marketing, finding volunteers or other helpful contacts can make all the difference to an intervention in being able to continue and flourish. Such help can come from local authorities, third sector organisations, faith groups, or even certain businesses or educational establishments.

**7. Access to advice on how to create partnerships, collaborate and overcome differences in culture with other organisations can help**

Perceived competition and lack of good communication are both reasons an intervention may fail to find and keep support in the community. When working with other organisations, differences in culture can be a problem as people will not be working with the same focus and goals. If staff have negative or competitive attitudes to other organisations, they may resist sharing information, learning and resources, which can stop partnership working effectively and thwart long-term sustainability.

**8. Access to advice on how to effectively plan and network to help find and manage funding and income can help**

External help such as training and advice on business planning and networking can make all the difference to the long-term prospects of a small intervention. Local authorities or large third sector organisations might be able to help with this. Sharing successful ideas with like-minded groups will help small interventions to find innovative funding solutions. For this reason interventions should be encouraged to include more practical detail on resources, costs and funding as part of standard reporting and evaluation.

**9. Commissioners should be flexible and accommodating of the challenges facing small groups regarding evidence gathering**

Groups in rural areas tend to be smaller in scale due to population and geography. This means they may struggle to produce statistics that rely on larger numbers, such as demonstrating demand, effectiveness and savings to health and social care services. With fewer staff, they may also find it challenging both to gather evidence and to continually apply for funding. To avoid disadvantaging rural areas in particular, it should be borne in mind that a one-size-fits-all criteria for how funding is allocated could mean small groups are not able to compete.



### **10. Policy makers should ensure policy meets local needs with adequate, protected and accessible resources attached**

If policy is focussed on medical needs and costs over social and emotional needs, then community-focussed groups and activities will struggle to sustain, as funders will not understand their benefits or see their cause as a priority. If there are changes in policy resources should be allotted and ring-fenced to match, or those resources will not be available in order to make the intended difference in practice.

### **11. Longer term funding, with simplified application processes, would help smaller initiatives with less capacity to continue**

If funding is always short-term, interventions will struggle to stabilise and will have to seek new ways to keep meeting costs continuously. This is particularly challenging for small-scale initiatives with fewer personnel and more limited time and resources. Longer term funding offers that are simple to apply for would help ensure smaller groups are not disadvantaged.

### **12. Longer term funding to support what is already being done will help retain and develop learning and practice on how best to meet local need**

Stability and reliability of provision is particularly important to service users living with dementia, but short-lived and inconsistent funding does not help this. New interventions will struggle to become established long-term as they are unable to plan ahead with confidence. They will also not have enough time to learn how local activity can be supported sustainably. Furthermore, if funding is always short-term and focussed upon new projects, then “quick win” projects will be encouraged over support for existing and experienced groups, meaning deep learning on what works to meet people's needs can be lost as a result.

### **13. Authorities and national organisations can help create conditions that encourage support for small initiatives, though policy, leadership and commissioning**

A disjoin between policy and local need can have a detrimental effect on an intervention finding support, as by adhering to one they will neglect the other. Practices that might encourage better support for small groups include ring-fencing funding specifically for dementia-targeted community initiatives; commissioning health and social care services to work with community initiatives; and developing health pathways around existing community networks. National and official organisations can also encourage a more strategic, joined up direction regarding community-based dementia support, by showing leadership in working with smaller, local initiatives and support for potential private sector partners wishing to do likewise.

For more detailed information on our recommendations for practice, please see our other booklet:

**Keeping Community Groups and Activities Going - Recommendations for Practice from the SCI-Dem Project**



# Acknowledgements

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**[www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

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### **The Association for Dementia Studies – Changing Hearts and Minds in Dementia Care**

Led by Professor Dawn Brooker, the Association for Dementia Studies is a multi-professional University research and education centre. We make a cutting-edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

If you think that we can help please feel free to contact us.

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